

Submission to the second independent review of the Personal Independence Payment assessment

About MND and the MND Association

- i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.
- ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop front-temporal dementia.
- iii. There are up to 5,000 people living with MND in the UK at any one time. It can affect any adult, but is most commonly diagnosed between the ages of 55 and 79. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.
- iv. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and groups, and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

The use of further evidence in claims for people with MND

- i. We believe that there are some key improvements that could be made to the Personal Independence Payment (PIP) assessment process to make better use of further evidence, particularly in order to help people with MND get paper-based, rather than face-to-face assessments.
- ii. It is important to first acknowledge the progress that is being made on further evidence systems. We find reports from the Department for Work and Pensions (DWP) and assessment providers about improvements encouraging. We understand that there have been promising developments regarding more realistic timescales for receiving and reviewing further evidence, and providers are starting to improve further evidence forms sent to GPs to try and get better quality evidence back. We hope that these developments and improvements will continue, and look forward to progress reports in these areas.

- iii. We have had discussions with providers and DWP officials about further improvements that could be made. We have outlined these here in order to help illustrate some of the ongoing problems that systems, and people with MND, face.

Putting guidance on paper-based assessments into practice: encouraging a common-sense approach

- i. The Department for Work and Pensions (DWP) PIP assessment guide states, in section 2.5.10, that:

In certain circumstances it should be possible to provide advice at a paper based review. Although each case should be determined individually, the following types of cases should not normally require a face-to-face consultation:

...

- *Claimants with severe neurological conditions such as motor neurone disease, dementia, Parkinson's disease, a stroke resulting in a significant impact on the claimant's functional ability – for example, those left with lasting neurological deficit such as left sided hemi paresis (the inability to move the left side of the body), etc.*

Despite this, we know that people with MND and Parkinson's have been required to have face-to-face assessments. We have seen cases where there is clearly sufficient further evidence from specialists in MND to demonstrate an entitlement to the higher rate of PIP, and yet they have still been asked to attend a face-to-face assessment.

- ii. The DWP and assessment providers say that this is because there needs to be clear medical evidence about the impact of a disability or health condition on someone's life. A diagnosis of a medical condition is not deemed sufficient evidence. We know that people with MND who have a DS1500 will not have to attend a face-to-face assessment, but we are less sure about claimants with other types of medical evidence, and what counts as sufficient.
- iii. While we understand that the PIP assessment is designed to investigate the impact of a disability on an individual's life, rather than making judgements on the basis of that disability, we also believe that the system needs to recognise that the impact of medical conditions like MND on someone's life is well documented; it is always progressive and always terminal, and while it will progress in different ways it will always have a profoundly disabling and permanent effect on a person's life. For this reason we believe that it should be possible to assess someone with MND on paper in the vast majority of cases.
- iv. We understand from assessment providers that in some cases further evidence is being sought or people are being asked for face-to-face assessments because, even though it is clear that the person has a severe medical condition which will clearly qualify them for the enhanced rate of PIP, assessors are not able to make a judgement against all areas of daily living. For instance, there may be sufficient evidence to determine that a person has a high level of need regarding washing

and dressing themselves, but no evidence about their level of difficulty completing tasks like communicating with others. In effect, back office assessors are having to make sure they 'tick' every box. The result is that people may be called in to determine how many points they score above the required threshold for higher rate PIP, even though it is already obvious to the assessor that they will definitely clear the threshold on the basis of the available information. The assessment therefore has no practical purpose – the person will receive the higher rate even without the extra information.

- v. Back office staff should be empowered to use the evidence available to award higher rate PIP if it is clear the person will qualify, without having to put evidence against every PIP criteria. We strongly recommend that both assessment providers pilot this approach for people with serious medical conditions such as MND to ensure that people with the disease are assessed consistently and appropriately across the country.

Health and social care professionals need to be better supported to return high-quality further evidence

- i. We are disappointed to hear from assessment providers that while further evidence is sought in a high proportion of cases, it is only returned in around 35% of cases. As stated earlier, we understand from one provider that work is being done to give professionals longer timescales and better guidance for returning evidence. However, we believe more could be done.
- ii. Firstly, there must be recognition that GPs are often not best placed to return further evidence, either because they do not have the time or they are not specialists in the claimant's needs and condition. More investment of resources must be committed to improving further evidence forms and tools for health and social care professionals who are better equipped to return high quality evidence, for instance specialist nurses. Forms should be specific regarding the kind of evidence that would be useful, and must explicitly encourage professionals to comment on whether a person is able to complete a task repeatedly, reliably, safely and in a timely manner.
- iii. Secondly, the DWP must seriously consider reimbursing all health and social care professionals for providing medical evidence, not just GPs. This would represent a welcome recognition that the time and the evidence they provide is at least as valuable as that which comes from GPs.
- iv. Finally the DWP itself must become more efficient at returning further evidence it holds. In cases where DLA recipients are being reassessed for PIP, claimants are able to request that evidence attached to their original DLA claim should be submitted and assessed to help determine their eligibility for the new benefit. This should not depend on a request from the claimant, who may not know that this is an option. Instead it should be done as standard, and the DWP must make every effort to retrieve and share DLA evidence with assessment providers in a timely manner.

Making PIP work better for progressive conditions

- i. The second independent review asks about what could be improved about the PIP process. We believe a new system is needed for people with MND and other progressive conditions, because the current system doesn't work for this group. There are two main issues with PIP for people with progressive conditions: the assessment does not encourage decision-makers to think about progression, and there is no lifetime award.
- ii. If someone with MND applies for PIP at a point where their needs are lower, they will likely be awarded the lower-rates of PIP. In cases where someone has a rare, slow-progressing form of the condition, this may well be appropriate. However, in the vast majority of cases this will mean that the person will very quickly need to be reassessed in order to secure them the correct, higher rate.
- iii. We understand from the DWP that decision-makers will set award review dates within a few months in these cases, where disease progression is recognised as a factor. We agree that this helps to ensure they get the right rate of award as soon as they are eligible. However, we question the logic of a system that, even though there is clear, indisputable evidence that someone has a health condition that will only get worse, that is terminal in all cases and that will in all likelihood progress rapidly, will not ensure that someone gets the highest rate of benefit straight away. We believe that there needs to be a separate system of passporting for people with progressive conditions like MND, which removes the need to keep reassessing someone who is initially placed on a lower rate. People with rapidly progressive conditions should be awarded the higher rate of benefit based on evidence not just of how their condition affects them on that particular day, but also how their condition is going to deteriorate, the extra costs they will have to meet when managing that deterioration and the fact that they will definitely qualify for the highest rate of PIP, usually within a very short space of time.
- iv. When DLA ended so too did the existence of lifetime awards. The rationale for this was that people with disabilities were too often 'left' on lifetime awards without receiving any additional help, or without ensuring that they still qualified for the same rate of benefit. However, this new system does not work for someone with a progressive condition; someone with MND will always see their condition deteriorate and their needs increase. Thus once they are awarded the higher rates of PIP, there is no logical reason for conducting any kind of reassessment. Lifetime awards must be re-introduced, at the very least for people with progressive conditions, in order to protect people with MND against the needless stress and anxiety associated with an award ending.

Comments on the second independent review of the PIP assessment

- i. While further evidence is a crucial part of the PIP assessment process, we are disappointed that the second independent review has chosen to set such narrow terms of reference. We believe that there are a range of issues regarding the delivery of PIP that this review will not examine.
- ii. It is difficult for organisations such as ourselves to comment on operational issues regarding further evidence, and indeed similar issues, because the DWP and assessment providers are often not forthcoming with information about these

issues. We have good relationships with all three bodies, and find that the providers in particular are able and willing to provide us with information about a range of different issues. However, operational processes are not laid out transparently, particularly by the DWP, so when trying to understand the full process it is often a matter of piecing together different bits of information from different bodies.

- iii. More openness about these processes and more joined up working between the DWP, the two providers and charities such as ourselves would help us to better understand the full assessment process, including issues regarding return of further evidence, and to jointly identify solutions to problems if they arise.

Our recommendations

- i. We recommend the following principles are built into the PIP assessment system in order to improve the experience and result for people with MND:
 - If there is sufficient supporting evidence that someone with MND is definitely entitled to the higher rate of benefit, they should be awarded this benefit even if the evidence available does not cover every area of daily living or mobility, without the need for either a request for further evidence or a face-to-face assessment
 - Systems, guidance and forms for submitting further evidence should be better designed to help all health and social care professionals submit high quality and relevant evidence in a timely manner
 - All relevant health and social care professionals should be reimbursed for providing supporting evidence for benefits claims
 - The PIP assessment should be redesigned to better take into account progressive conditions, the extra costs associated with managing a deteriorating state of health and the speed of progression of a disease like MND
 - People with progressive conditions who qualify for the highest rates of PIP should be given lifetime awards
 - The DWP and assessment providers should be more transparent about assessment operations and should work in a more joined-up way with charities and representative groups to identify solutions to problems if they arise.

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